You had a laryngectomy…

Some answers to your questions

Helpful information for recent laryngectomees

Revised: May 2021

Acknowledgement

The *Association québécoise des laryngectomisés*, founded in 1979 as the *Fédération québécoise des laryngectomisés*, is pleased to present this document that will answer many of the questions that each new laryngectomee and his relatives are entitled to ask themselves when they are facing many unknowns.

The document was first published in 1986 under the leadership of the founder of the laryngectomees grouping in Quebec, Mr. Jean-Paul Tardif, inspired by a publication of the Florida Association and thanks to the authorization obtained from the Mayo Clinic in the USA to translate and adapt their "Guide to the Laryngectomized, Hope".

"If you had a laryngectomy… Answers to your questions”, originally known as « To help shed a little light…», is now in its fourth revision, inspired by the questions and concerns of laryngectomees and their loved ones met during the pre- and postoperative visits of our visitors-volunteers, or at events organized by the Association, such as Coffee Meetings, or submitted in surveys.

We hope you will find as much satisfaction in reading this document as we have found to revise it for you.

The president,
Association québécoise des laryngectomisés

Forward

To speak and express one's thoughts and needs through speech is such a natural and normal process that it is hard to imagine what life would be like without speech. It is astonishing to learn that life can go on after the loss of one's larynx.

Laryngectomy surgery is a type of operation not much talked about in the media. Therefore, it is not surprising that little is known about it.

If you yourself have recently undergone a laryngectomy, your doctor undoubtedly explained to you all the reasons why it was necessary to remove your larynx and vocal cords.

The *Association québécoise des laryngectomisés* offers this booklet to help you better understand what has happened to you. Here you will find answers to the main questions you may be asking yourself or that you will find yourself asking during the first months of your convalescence.

This booklet is not meant to take the place of information and advice given to you by your physician, your speech pathologist or your nurse. Its aim is to draw on the experiences of others who have undergone a laryngectomy in order to help you overcome the difficulties you encounter and so that you may continue to live a rewarding life.

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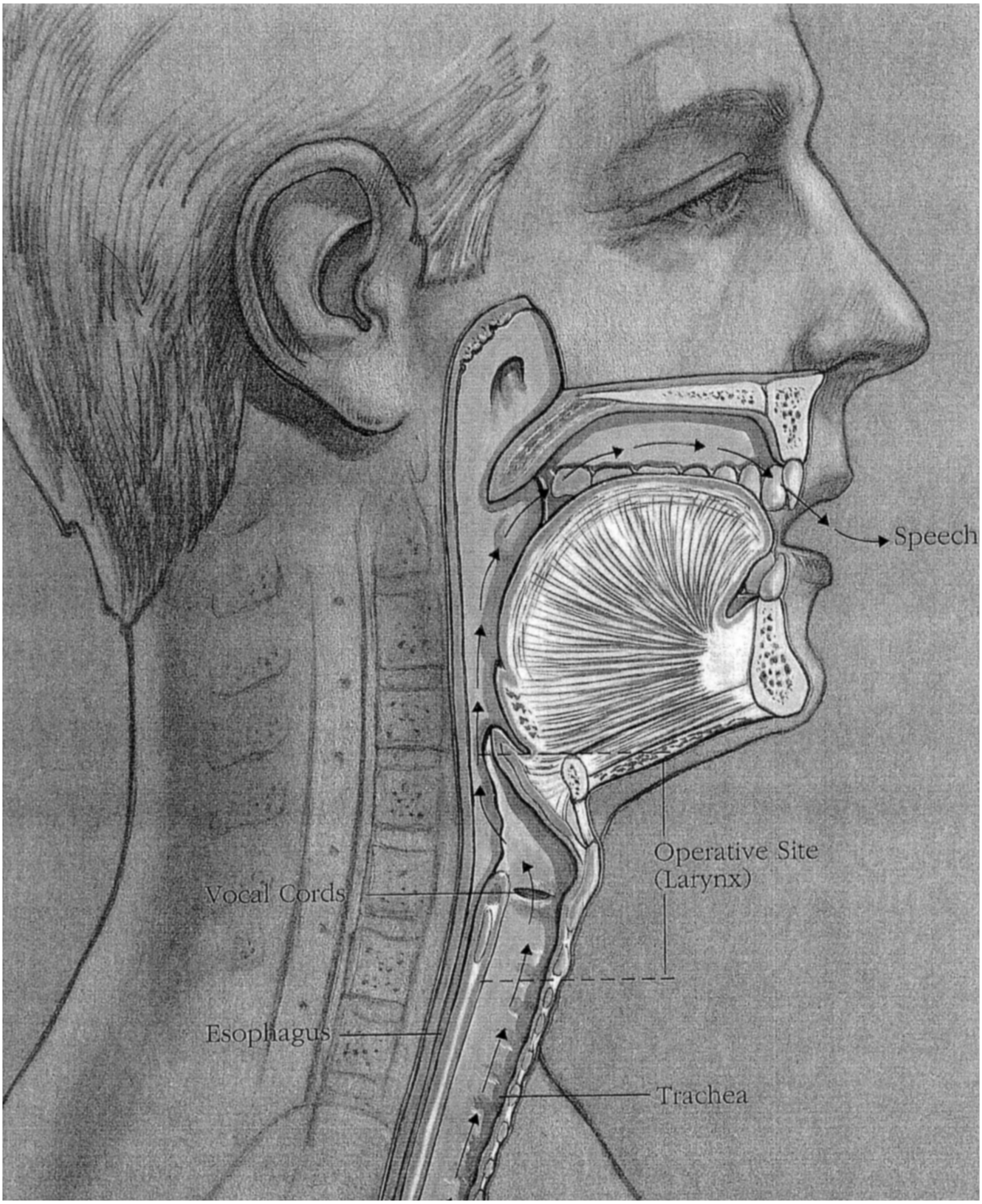
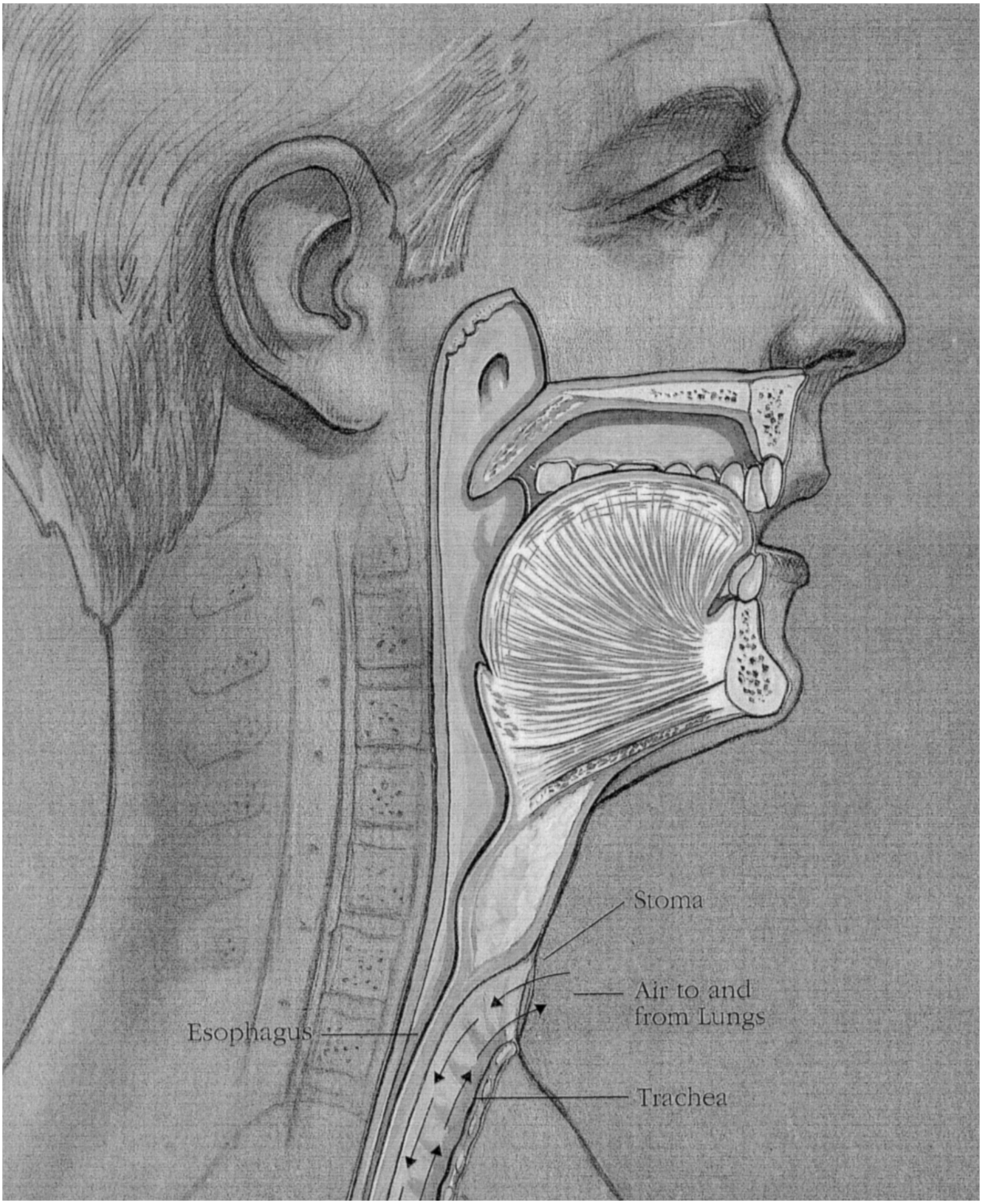
Before Laryngectomy



After Laryngectomy



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Part one
The operation and its main effects

1. **Q. What is a total laryngectomy?**

   A. It is a surgical operation which removes the entire larynx. The larynx is called the “organ of speech”. It is situated in the throat at the end of the trachea (respiratory canal) in front of the esophagus (alimentary canal). It contains the vocal cords (see illustrations page 4 and 5).

2. **Q. Why is a laryngectomy performed?**

   A. Most often, the surgeon removes the larynx because he has discovered a malignant tumor on the vocal cords or in the throat and neck.

3. **Q. Why must there be an opening in the neck?**

   A. When the larynx is removed, the trachea becomes disconnected from the nose and mouth. The air cannot go from the lungs to the mouth anymore. The doctor has no choice to bend the top of the trachea and connect it to an opening that he has made in front of the neck so the person can now breathe through this opening.

4. **Q. Will I always have to breathe through this opening?**

   A. As you have had a total laryngectomy, the answer is yes. Medical researchers have been working on ways to rebuild a voicing process and airway, but the complexity of these functions poses them a huge challenge requiring more research.

5. **Q. What is the name of this opening in my neck?**

   A. The surgical procedure is called a tracheotomy. The opening made by the procedure in front of the neck is called STOMA.

6. **Q. How long shall I have to wear the cannula in my stoma?**

   A. Your doctor will tell you what is best in your case. You will find out, by talking with other laryngectomees that some of them wear it all the time; others only at night and most of them stop wearing it after a time. Removal of the cannula is often gradual.

7. Q. Will I have trouble swallowing?

A. During the operation, the doctor must reconstruct a part of the alimentary canal. After the postoperative feeding protocol to ensure proper scarring of the throat tissue and let your esophagus rest, you are going to be gradually brought to eat as before. Many laryngectomees do not have that much trouble swallowing after leaving the hospital but, for others, it might sometimes be necessary to follow a prescribed diet and modify their eating habits for a while. It is recommended however to eat slowly, chew and swallow small mouthfuls of food at first, take liquids with food and avoid sticky or hard to chew food. On these points, patience will be your best ally.

8. Q. How long will I have to see my doctor for periodic checkups?

A. Your doctor has surely informed you about the needed regular checkup visits and its importance to follow the schedule set up for you. You will feel better and be less worried about your health in the months and years ahead if you accept these periodic examinations which can detect possible complications.

Part two
Basic care and precautionary measures

9. Q. It is important to clean the cannula. How is this done?

A. It is important to keep your cannula clean. How often you clean it depends mostly on the amount of secretion that builds up inside the cannula and on other possible causes of clogging: dry air, smoke, dust of all kinds, etc. To clean your cannula, soak the two pieces in hot, soapy water; use a cylindrical brush to clean the inside. Rinse under hot water and dry the pieces by shaking them. Don’t use a towel or tissue.

10. Q. What are the reasons to protect my stoma from dust?

A. As you can no longer depend upon your nose to filter, warm and moisten the air you breathe, you are more sensitive to various irritants like dust, allergens and certain chemicals like gasses or vapors. Some people are even affected by "normal house dust" when they do not wear filters. In short, there are a thousand and one reasons for protecting your stoma with a filter.

11. Q. How can I tell if I have breathed in some harmful dust? What can I do about it?

A. Normally, after breathing in some harmful dust, you will feel like coughing up heavier secretions than usual. Quickly cover your stoma and move to a place where the air is cleaner. Some types of irritating and corrosive dust particles take effect after a few hours. You will see a change in the color of the secretions which will also become more gluey and stickier. To avoid being inconvenienced by dust particles of all kinds, always cover your stoma with an appropriate protector.

12. Q. What kind of filter should I use to cover my stoma?

A. The type of filter depends on your needs and comfort; it is the use of one that is important. There are many types of filters. In Quebec, the Supraregional programs for laryngectomees (SALPAC) of the *CHUM* and the *CHU* de Québec offer open fabric filters, foam filters or heat and moisture exchanger devices called HME. Some are free, others are sold by private companies. Stoma covers are also available from the Association. Discuss it with your speech pathologist or the professionals who care for you. The goal is always to filter the air one breathes and to guard against irritants.

13. Q. Are there any other precautions to take?

A. When you take a bath or a shower, be sure that the water does not enter your stoma. When boating, make sure you use a sturdy boat and take with you a life jacket which allows you to keep your head and shoulders out of the water in case of an accident. As well, do not risk eating any food when you are lying on your back, especially if your stoma is not covered.

14. Q. Why does so much secretion accumulate in my stoma in the morning?

A. Have you ever counted how many times you must clean your stoma during the day? Surely many times. What happens while you sleep? Except on rare occasions, you do not feel the same need to clean your stoma. Yet, secretions do form in your trachea **24 hours a day**, even during the night. As a result, it is not surprising that there is a certain accumulation after 8 hours of sleep. When a person is not laryngectomized, the secretions from the lungs and trachea are coughed frequently during a normal day, ending up in the pharynx with the mucus coming from the nose, and without even noticing it, is swallowed with the saliva automatically all day and even during the night. After a laryngectomy, because there is no more connection between the trachea and the pharynx, the buildup of secretions from the lungs and the trachea stops at the stoma and you must clean it with a handkerchief.

15. Q. How can I best clear my stoma?

A. Usually, it is enough to cough while placing a handkerchief in front of your stoma. The coughing brings up the secretions that have accumulated in the respiratory canal. It is good advice to bend forward when doing so, and the secretions will find easier way to come out. Your healthcare provider has given you instructions on how to clean your stoma: make sure you gather the supplies you need. If you notice a slight trace of blood in the secretions, it might tell you that the humidity is too low, and your windpipe becomes dry and bleeds. This is rather frequent. However, if it persists with appropriate humidity or there is a large amount of blood consult your doctor.

16. Q. How can I take care of my secretions without attracting attention when I am in a group?

A. Most of the time you will feel that there is something that is present in your trachea. In that case, just go to privacy to eliminate the secretions.

17. Q. Can cold weather irritate my stoma?

A. If the stoma has healed well, cold weather will not irritate it. However, cold air entering your trachea through your stoma could irritate your windpipe and lungs. Do not forget that the air you breathe in now is no longer warmed by first passing through your nose. In cold weather, it is a good idea to create a kind of warm air space in front of your stoma by wearing a filter and even a scarf when it is quite cold.

18. Q. Can I blow my nose?

A. Before the operation, the air was propelled from your nose by your lungs. After the operation, this air pressure is much less as it comes only from the mouth and the back of the throat. Saying so, different methods still exist to force the air from your mouth through your nose with more or less results. Laryngectomees who use a tracheo-esophageal prosthesis may be able to blow their nose by occluding the stoma and passing air through the pharynx and nose.

19. Q. Can I take a shower? Wash my hair?

A. Certainly. To guard your stoma, get yourself an appropriate protector. Your association will provide you with a first shower collar for free. Should you take a shower without using a protector, make sure the water sprays in such a way so as not to get into the stoma. If you are afraid of the shower, wash your hair in the kitchen sink. Remember that: whenever there is a risk that water might enter your stoma, just place your hand or a washcloth in front of the opening. This basic rule will help you to adapt to any situation.

20. Q. Why do laryngectomees require more humidity?

A. Before the laryngectomy, the air is inhaled by the nose where it becomes warm and humid before entering the lungs. After laryngectomy, the air is not inhaled by the nose anymore and enters directly in the trachea by the stoma. Cold, dust and dry air become irritating for the airway. Many feel the need of extra humidity in their homes. A humidifier can be installed in the house and an extra one in the bedroom if necessary.

21. Q. If I am in an accident or if I pass out on the street, what will happen to me?

A. We suggest that you keep in your wallet the card "In case of emergency" provided by your Association which contains information on your condition as a laryngectomee. Moreover, it would be wise to wear a medical alert bracelet on your wrist. It would also be good for your family to know the method of artificial respiration appropriate to your condition.

Part three
Some restrictions…but bearable ones

22. Q. I was a smoker. Now what?

A. According to the Canadian cancer society, smoking is the main risk factor for developing cancer of the larynx and the lung and people who continue to smoke after treatment for laryngeal cancer have a greater risk of developing a second head and neck cancer than people who quit smoking. Some laryngectomees have made it their mission to meet young people to encourage them not to start smoking.

23. Q. Can I take a little drink from time to time?

A. For most people, drinking alcohol is part of the pleasure of a good meal, in good company. There is no problem when done with moderation.

24. Q. Will my sense of taste return?

A. This varies from person to person, particularly after radiotherapy. In time, you will probably taste all kinds of food; perhaps not with all the nuance and subtleties you had before, but sufficiently to appreciate the pleasure of dining. Many laryngectomees consider they have quite recovered their sense of taste.

25. Q. Will my sense of smell return?

A. After the operation, because you do not breathe through your nose anymore, you will not smell the odors automatically has you did before. But there are techniques you can try to send air through your nose to experiment smelling odors again. Strong odors or those that move quickly in the atmosphere are easier to capture. However, the most frequent complaint remains the persistent problem of smelling.

Part four
Back to work

26. Q. Do you think I will be able to return to my work? How soon?

A. Returning to work after the operation depends on several factors, including of course your state of health, but also on the function occupied before the laryngectomy. Some laryngectomees, close to retirement age, opt for this alternative. We all know laryngectomees who have returned to work but also others who have been forced to give up. As for the precise time when you can return to work, this is a question your doctor will be able to answer. If your employer is reluctant to take you back, consult the hospital's social worker or ask for the help from the Association to guide you in the process.

27. Q. Are there special precautions I should take when returning to work?

A. Take care to cover your stoma so that no dust or foreign particles get in. Also, by making, if possible, a gradual return to work, you will increase your stamina.

28. Q. Is it true that I will no longer be able to lift heavy loads?

A. You no longer have your larynx to lock in the reserve of air required by your lungs while making that effort; but you still have your arms and your muscles to compensate. If you are not as good a "piano-mover" as before, you are still capable of making the efforts required by a normal active person.

29. Q. What can I do if I have financial problems?

A. Should financial difficulties exist, consult the social worker attached to your hospital center. Your nurse, doctor, or speech pathologist will provide you with the necessary referral. Your Association will also guide you if you wish.

Part five
Rehabilitation, Speech Therapy, Communication

30. Q. Rehabilitation and speech therapy. Would you tell me something about these programs?

A. The FIRST part of the program teaches you to look after yourself. This means taking care of your stoma yourself. This will increase your self-confidence and make you feel more secure. Follow your nurse's advice. At home, arrange your bathroom (mirror, lights, toilet articles, etc.) in such a way that you can take care of yourself without help.

The SECOND part of the program helps you to establish communication. There are three main ways of doing this:

a) by developing esophageal voice;

b) by using an artificial voice source called artificial larynx;
c) by using a tracheo-esophageal prosthesis.

Your speech pathologist will provide you with all the information and guide you to participate in a speech therapy program.

The THIRD part of the program aims to help you to get back to a normal life within society, in your family circle and, if it applies, in your work milieu. Laryngectomees, in most countries of the world, get together to form associations where they feel at ease to discuss matters and learn from the experience of others.

31. Q. How can I communicate while learning to speak again?

A. You can write down what you want to say (paper and pencil or magic pad). You can also try to communicate by forming words with your lips and mouth (without making sounds). Articulate your words carefully so that those looking at you can "read" your lips correctly.

Your speech pathologist will also offer you to learn to use an artificial larynx as soon as possible after your operation, while you are still in hospital. Remember that others want to communicate with you and that they become upset when they do not understand what you want to tell them. Be natural and understanding with others; ask them if they understand you. Your attitude will greatly reduce their anxiety.

32. Q. What is esophageal speech?

A. In a laryngectomee, the esophagus (alimentary canal) assumes the role of the removed larynx and vocal cords, hence the name, esophageal speech. Someone using the esophageal voice first pushes the air from his mouth back into his esophagus. He then expels it by vibrating the muscles in the upper portion of the esophagus, producing a sound which is then modulated by the mouth to articulate words, producing intelligible speech.

33. Q. What is an artificial larynx?

A. It is a device which produces vibrations to create a substitute voice. These vibrations replace the sounds you make with your vocal cords before your operation. They are transmitted to the mouth and become words and sentences when the syllables are well pronounced. There are different models of artificial larynx and your speech pathologist can offer you one that suits you.

34. Q. What does the following phrase mean?
"To speak with a T.E.P." (tracheo-esophageal prosthesis)

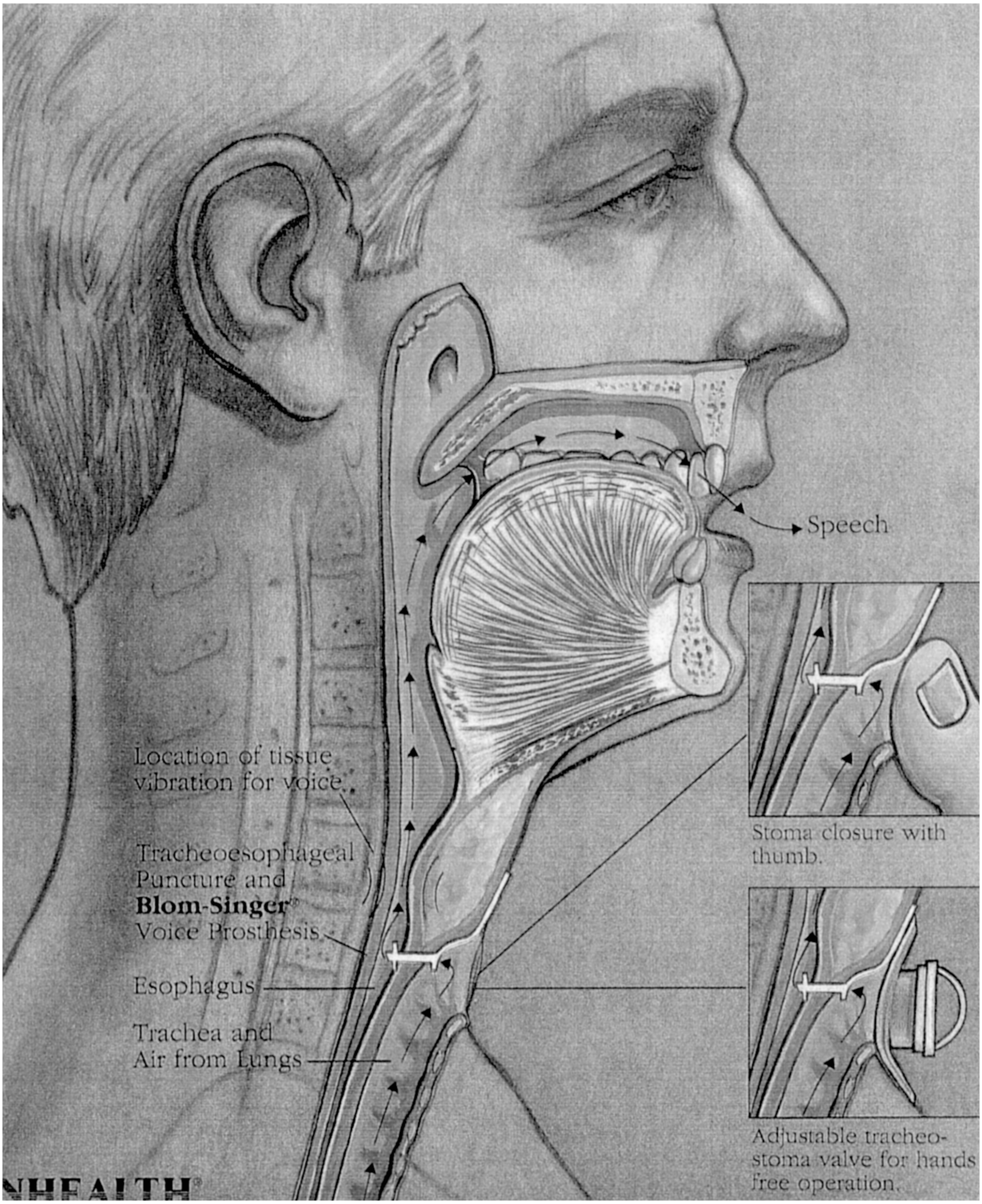
A. Before losing your larynx and vocal cords, you used the air exhaled from your lungs to speak. Since the operation, the air exhaled from your lungs no longer reaches your mouth; it now comes out through your stoma.

The T.E.P. resembles a small plastic cannula that is inserted in a fistula created through the wall that separates your trachea and your esophagus to let the air exhaled from your lungs to get to your mouth. (See next page).

As the air is exhaled, the laryngectomee blocks off his stoma with his finger or a valve to force the air to go through the prosthesis and hence to the mouth. Thus, a vibration is created, a sound that one must only articulate to obtain words.

The laryngectomee generally manages to talk easily and rapidly with a tracheo-esophageal prosthesis. This option requires some maintenance that must be rigorously evaluated before making this choice.

Tracheoesophageal Voice Prosthesis



35. Q. Do you think I will be able to learn to talk?

A. A great majority of laryngectomees today learn to speak using either esophageal speech, an artificial larynx or a T.E.P. Follow the advice of your speech pathologist, observe your fellow laryngectomees and you will find a way of communicating which corresponds best to your abilities.

36. Q. If I want to learn to speak, when can I start?

A. As soon as your doctor judges that you have recovered sufficiently, he will tell you to start speech therapy. In some cases, this permission may be held back or suspended temporarily due to complications or the need for further treatment.

37. Q. How long will it take me to learn to talk?

A. Many factors can influence the length of the duration. If you choose to use an artificial larynx, learning is quite short; you may be able generally to speak within a week of your surgery.

If you choose to go for the T.E.P. you will be speaking very shortly after the implant of the prosthesis.

If you intend to learn a good esophageal speech, the learning time may vary among laryngectomees from a few weeks to a few months. Your speech pathologist will explain the different factors that may influence the length of the learning process.

38. Q. Do I have to find my own speech pathologist?

A. That will not be necessary. In almost all Quebec hospitals where laryngectomies are performed, there is a speech pathology department. Speech pathologists are professionals qualified to teach you how to speak. One of them will visit you first before your operation, then when you are ready to experiment an artificial larynx before you leave the hospital. Your doctor will inform the speech pathologist as soon as you are able to go on with esophageal speech or T.E.P. If there is no speech pathology department in the hospital where you had your surgery, your doctor will direct you to the nearest speech center.

39. Q. Will I be able to speak on the telephone?

A. Whether you use esophageal speech, tracheo-esophageal speech, or an artificial larynx, you will be able to speak on the telephone. The telephone automatically increases the volume of your voice. The important thing is to pronounce each word very distinctly, to speak slowly and clearly without forcing your voice and to be sure to place the phone directly in front of your mouth. But watch out! If you can only whisper, you will not be heard over the phone. If you do not produce sound, your phone is helpless.

40. Q. Should I participate in get-together with family and friends? How will people react to the way I make myself understood?

A. Do not isolate yourself. Go to your friends and to your relatives. They are waiting for this gesture on your part so they, in turn, can visit you. Do not worry about how they will react; they are interested in knowing your thoughts, your reflections, no matter what means you use to communicate. When you can finally talk, they will be just as happy as you. Since your voice will be at a lower volume, it might be a good advice to raise your hand to signal to your audience that you would like to say something. You will be amazed to see how much they listen when you talk.

41. Q. Is it true that esophageal speech fails in times of emotion and anger?

A. When we are either emotionally moved or angry, all the muscles of our body become tense. This is especially true of the throat muscles. Before your operation, did you ever try to swallow a mouthful of food when you were upset? Well, it is these same throat muscles which must expand and contract for esophageal speech. If, for some reason, these muscles cannot relax, esophageal speech is not possible.

Part six
Social Life

42. Q. When people see the hole in my neck, won't they turn away from me?

A. For many reasons, you do not leave your stoma uncovered. Moreover, you do not leave your stoma uncovered for people to see. You will see many laryngectomees wearing shirts and ties, ascot ties, scarves, turtlenecks, or various types of stoma covers. Nothing else need to be changed in your way of dressing. Overall, you will realize that most people will not react at all on the fact that you block the exit of air from your throat to speak. They will certainly realize that your voice is different and that's it. You have probably been among laryngectomees, men and women, on the street, in the subway, at the theatre, without even suspecting that these persons breathed through an opening in the neck because these people were dressed like everyone else.

43. Q. Is it normal for me to feel embarrassed about my condition?

A. Anyone can become anxious when there is a change in the way he looks or acts. Think of those who have all their teeth taken out, of a woman who has had a breast removed, of someone who loses all his hair, etc. Do not isolate yourself, modern medicine has given you a chance to extend and enjoy life again. Come meet other laryngectomees and learn how to overcome your embarrassment. Professional may also help you overcome this difficult period of your life.

44. Q. Will my spouse and I find it difficult to get along?

A. Living together demands constant adjustment. This is even more so when one of the two has had his appearance and his way of functioning altered by surgery. The fact of not being able to talk might increase the chances of being misunderstood. Both parties must exercise patience during the period of readjustment. Clear up any misunderstandings. Remember that your loved ones also had a shock when learning of your laryngectomy. The people you care about want to help you but also must live their emotions. Be patient, make them comfortable in your presence, they will be grateful.

45. Q. Will meetings with other laryngectomees be helpful?

A. You will feel much more at ease if you make your first steps in conversation with people who have faced the same problems or with volunteers who are used to speaking with laryngectomees. It will also give you the chance to meet people who are ready to share their experience and to respond to your concerns. At these meetings, the spouses of laryngectomees can meet other spouses as well as volunteers who will help them cope more easily with the period of readjustment.

Part seven

Centers Offering Information and/or Services

46. Q. If my family or myself wish to get more information, where can we obtain it?

A. You may call or come to the:

Association québécoise des laryngectomisés
5565 Sherbrooke street East, 5th floor
Montréal, Québec H1N 1A2
Phone: 514-259-5113 or, toll free, 1-844-285-2335
Fax: 514-259-8946
Email: info@aqlar.org
Web site: www.aqlar.org

Quebec's Ministère de la Santé et des Services sociaux (MSSS) subsidizes two laryngectomee Centers: they can provide all the services you need, including information, needed products and communication training.

For Eastern Quebec residents:
Centre hospitalier universitaire de Québec (CHU de Québec)
Service aux laryngectomisés - Programme d'aide à la communication (SAL-PAC)
Hôpital Hôtel-Dieu de Québec
11 Côte-du-Palais, room 1565
Québec, Québec G1R 2J6
Phone: 418-691-5095
Fax: 418-691-5377
Email: programmesalpac@chudequebec.ca
Web site: www.chudequebec.ca (write SAL-PAC in the research box)

For Western Quebec residents:
Centre hospitalier de l'Université de Montréal (CHUM)
Service aux laryngectomisés - Programme d'aide à la communication (SAL-PAC)
1000 St-Denis Street
Pavilion C, 9th floor
Montréal, Québec H2X 0C1
Phone: 514-890-8236
Fax: 514-412-7899
Email: sal-pac.chum@ssss.gouv.qc.ca
Web site: www.chumontreal.qc.ca/patients/sal-pac

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AQL Association québécoise
des laryngectomisés

5565 Sherbrooke street East
Montréal, Québec H1N 1A2

Phone: 514-259-5113 or, toll free, 1-844-285-2335
Fax: 514-259-8946

Email: info@aqlar.org
Web site: www.aqlar.org